

Transparency Statement from the EU Transparency Register – no. 047603512537-13:

<http://ec.europa.eu/transparencyregister/public/consultation/displaylobbyist.do?id=047603512537-13>

European Dysmelia Reference Information Centre

Identification number in the register: **047603512537-13**

Registration date: **04/01/14 18:09:27**

The information on this organisation was last modified on **05/01/14 16:43:09**

The date of the last annual update was **04/01/14 18:09:27**

Registrant : Organisation or self-employed individual

Name/company name: **European Dysmelia Reference Information Centre**

Acronym: **EDRIC**

Legal status: **Förening**

Website address: <http://www.dysnet.org>

Sections

Section: **III - Non-governmental organisations**
and more precisely: **Non-governmental organisations, platforms and networks and similar**

Person with legal responsibility

Surname, Name: **Mr Geoff Adams-Spink**

Position: **Board Chairman**

Permanent person in charge of EU relations

Surname, Name: **Mr Tobias Arndt**

Position: **Chief Operating Officer**

Contact details:

Contact details of organisation's head **2 Axelstorpsvägen**
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SWEDEN

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Goals / remit

Goals / remit of the organisation: **EDRIC is an international umbrella organisation representing currently 23 member associations with about 4 000 individuals in 17 European countries. EDRIC was founded in 2009 and is registered as a non profit organisation in Sweden. Dismelia covers over 40 different rare disease syndromes and conditions under the common topic of limb differences. Scientific estimates indicate an average incidence of 50 in 100 000 live births.**

Limited availability of services account for a variety of health issues, including infant mortality, consequential damage, erosion of quality of life, premature ageing, lower life expectancy and other. EDRIC's overarching mission is to reduce these massive health inequalities by making best practice available everywhere in Europe and beyond, through expertise networking and information dissemination, thus generating substantial added values for patients and health systems in Member States.

The organisation intends to join forces between national patients' associations and functions as an intermediary for cooperation and exchange of information and experience as well as an advocate, representing the rights of patients and people with disabilities living with limb differences.

EDRIC believes that patient associations are uniquely placed to understand as well as advocate for the many unmet needs of patients. These associations provide invaluable support to patients and health service providers in a wide variety of areas, such as advocacy on patient interests, providing accessible and understandable information, practical advice and psycho - social support.

- The organisation will work towards common objectives with all relevant stakeholders: health professionals, governmental and regulatory agencies and commercial providers.

- EDRIC recognises the need for global expansion and wishes to share knowledge and network with other organisations outside of Europe.

- EDRIC is in the process of implementing a three level interacting community and network architecture to support a patient - centric and empowerment value chain aimed at reducing health inequalities. This consists of:

- o Dysmelia Network (DysNet) peer-support community,**
- o Dysmelia Knowledge Base (DKB) which are both already implemented,**
- o Dysmelia expert network (DEF) for proactive partnerships to be launched in 2014 and fully implemented in 2015 and a Dysmelia European Reference Network (DysERN) for birth defect and**

**limb dysfunction rare diseases
scheduled for 2014-2017.**

The organisation's fields of interests are: • **global**

**Number of persons engaged in activities falling under the scope of
the Transparency Register**

Number of persons: **1**

Complementary information:

Persons accredited for access to European Parliament premises

First name	Surname	Start Date	End Date
Tobias	Arndt	29/01/14	28/01/15

Activities

Main EU initiatives covered the year **none**
before by activities falling under the
scope of the Transparency Register:

Fields of interest for e-mail alerts on consultations and roadmaps;

Fields declared by the organisation:

- **Consumer Affairs**
- **Education**
- **Employment and Social Affairs**
- **Information Society**
- **Internal Market**
- **Justice and Fundamental Rights**
- **Public Health**
- **Research and Technology**
- **Youth**

Structure

Total number of members that are natural persons: **0**

Number of member organisations: **23**

Member organisations (*Number of members*) :

- **Föreningen för de Neurosedynskadade (FfdN) (204 members)**
- **Thalidomide Trust (469 members)**
- **REACH Charity Ltd (1,200 members)**
- **Irish Thalidomide Survivors Society (ITSS) (14 members)**
- **Den Norske Thalidomide Forening (17 members)**
- **Asociación de Víctimas de la Talidomida en España (AVITE) (330 members)**
- **Thalidomidici Italiani ONLUS (314 members)**
- **Contergan NRW (800 members)**
- **A.V.S.B. (32 members)**
- **Ragguingere (300 members)**
- **Associazione Italiana Sindrome di Poland (AISP) (250 members)**
- **Hilfswerk für Contergangeschädigte e.V. Hamburg (HICOHA) (160 members)**
- **Interessenverband Contergangeschädigter und deren Angehörige Köln (170 members)**
- **Contergangeschädigte Hessen e.V. (390 members)**
- **Contergan Austria (12 members)**
- **In Our Hands (18 members)**
- **PiP UK (23 members)**
- **Assédea (140 members)**
- **Thalidomide Society (260 members)**
- **Stichting NESOS (21 members)**
- **TARS (17 members)**
- **FfdN Stockholm (83 members)**
- **FfdN Väst (121 members)**

The organisation has members/is represented in the following country(countries):

- **AUSTRIA**
- **BELGIUM**
- **CYPRUS**

- DENMARK
- ESTONIA
- FINLAND
- FRANCE
- GERMANY
- GREECE
- IRELAND
- ITALY
- MALTA
- NETHERLANDS
- POLAND
- SPAIN
- SWEDEN
- UNITED KINGDOM

Complementary information:

Networking

Information on (i) organisation's membership of any associations/federations/confederations **EURORDIS** or (ii) relationships to other bodies in **European Disability Forum (EDF)** formal or informal networks.

Financial data

Financial year: **01/2012 - 12/2012**

Total budget:	148,300€
of which public financing:	€
- from European sources:	
- Procurement:	€
- Grants:	€
- from national sources:	€
- from local/regional sources:	€
from other sources:	148,300€
- donations:	142,950€

- contributions
from members: **1,800€**
- **Financial**
income : **3,550€**

Estimated costs to the organisation directly < **50000 €**
related to representing interests to EU
institutions in that year:

Other (financial) information provided by the
organisation: **Expenss for the activities under
the register are well below € 10
000 per year.**

Code of conduct

By its registration the organisation has signed the Transparency Register Code of Conduct.